

Principal Points of Alexander L. Napolitano
Executive Director, Bethesda Lutheran Home, Watertown, Wisconsin
In Opposition to S. 2053: The Community and Family Living Amendments of 1983

I. BETHESDA'S EXPERIENCE: Founded in 1904, Bethesda serves 470 retarded children and adults from 31 states and one foreign country on our main campus in Watertown, WI. We also operate 10 group homes in eight states, have three more under development (total: 103 beds), and this month acquired Faith Village in Kansas (three 15-bed cottages plus two 10-bed group homes, for a total of another 65 beds). Our services include residential care, educational and vocational training, medical and nursing care, religious instruction, psychological and social services, and therapies (occupational, physical, speech, music and recreation).

II. POSITION REGARDING S. 2053: For the reasons stated in our written testimony entered at the Feb. 27, 1984, hearing and summarized in today's testimony, we believe S. 2053 will disserve the interests of America's retarded citizens.

III. REACTION TO AMENDMENTS PROPOSED BY VARIOUS ADVOCATE GROUPS

A. We AGREE with the following proposals:

1. Retarded persons over age 65 should have access to Medicaid-funded nursing home care, when needed, without any time limitation.
2. Protective services and case management should be available (but not mandated) for any disabled individual, regardless of income or assets.
3. The appeal process should be extended to those receiving services in the community, and should not be reserved only for those in institutions.
4. Medicaid should be available to needy children living at home.

B. We DISAGREE with the following proposals:

1. Phasing down to only 15% of Medicaid funds now expended for residents in institutions. This is an improvement over the total phase-out concept, but it would still have the effect of closing most institutions (including excellent private ones that are supported in part by private contributions).
2. Requiring private facilities to meet the wage standards of public institutions - this is an infringement on the rights of private enterprise.
3. Funding the training of workers. No other industry has this privilege.
4. Establishment of higher professional fee levels and funding of extensive personalized services. The resulting cost would be prohibitive.

IV. WHAT WE SUGGEST: Let's agree on certain basics; then seek solutions together.

Basics: 1) Criteria should be: basic needs of the individual and quality of program. Excellence, not size, should be the benchmark for providers.
2) Costs of proposed programs must be assessed appropriately, comparing apples with apples, and must not unduly overburden the taxpayer.
3) The principles of states' rights and private enterprise must be upheld.
4) We must concentrate on the most needy: those who have severe or profound retardation, behavioral problems and/or multiple physical disabilities.

Proposals: 1) Insist that existing laws be enforced for every institution in this country to eliminate abuse and improve programs. If we can't inspect and correct now, how can we enforce new laws on thousands of new group homes?
2) Expand the Medicaid waiver and give that concept permanence; encourage all states to utilize the ICFMR option already available under Title 19.
3) Assess the quality of life from the viewpoint of individual clients - their personal preferences, needs and abilities - rather than our own perspective. What is best or normal for you or me may not be that for a very retarded person or one who is elderly, medically fragile or has behavior problems.
4) Let us move slowly, through trial and testing, to assure success rather than experimentation with the lives of precious people - our retarded citizens.

STATEMENT OF ALEXANDER L. NAPOLITANO
ON BEHALF OF BETHESDA LUTHERAN HOME
WATERTOWN, WISCONSIN 53094
Regarding Proposed Amendments to S. 2053
THE COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983
Before the Health Subcommittee
of the Senate Finance Committee
August 13, 1984, at Minneapolis, Minnesota

As Executive Director of Bethesda Lutheran Home, 700 Hoffmann Drive, Watertown, Wisconsin 53094, I would like to thank the Subcommittee for this additional opportunity to comment on S. 2053 and some of the amendments which have been proposed by various professional and advocate organizations - and for the opportunity to offer the suggestions of our organization regarding better ways to meet the needs of retarded individuals.

I. BETHESDA'S EXPERIENCE

A. History: Since 1904, Bethesda Lutheran Home has served over 2,600 retarded children and adults, earning a nationwide reputation for excellence in the field. Currently we serve over 470 retarded individuals from 31 states and one foreign country on our main campus in Watertown, Wisconsin. We also operate 10 group homes in eight states and have three more under development, for a total of 103 licensed beds. Just this month, we have also acquired Faith Village in Kansas. This consists of three cottages of 15 beds each in Shawnee Mission and two 10-bed group homes in Olathe.

B. Services: Located on 475 acres along the scenic Rock River, our main campus includes dormitories, a vocational workshop, therapy rooms, an infirmary, detached small group homes, an educational center, a chapel, service buildings and extensive

recreational facilities (gym, swimming pool, arts and crafts, ball diamonds, playgrounds, outdoor shelters, and a large wooded campground). Bethesda employs a staff of 600 people, including doctors, nurses, therapists (occupational, physical, speech, recreation and music), psychiatrists, psychologists, residential aides, chaplains, teachers, social workers, a pharmacist, medical technologist, librarians, and a volunteer coordinator (who works with the more than 5,000 volunteers who befriend, chaperone, assist and provide special entertainment for our residents, donating over 70,000 hours each year).

C. Goals: Through treatment and training programs, Bethesda strives to help retarded individuals develop their talents and abilities to their fullest potential, thereby enabling them whenever possible to live satisfying and productive lives in the community. A complementary goal is to instruct them in the Christian faith so that they can experience the joy of a Christian lifestyle.

In addition, we are concerned about the thousands of retarded persons in this country who do not have access to religious instruction in their local community, and for this reason we have developed an Outreach Program to prepare churchworkers for teaching retarded children and adults in local parishes. We are also developing a Christian Resource Center as well as a Diagnostic and Evaluation Center. We publish curriculum materials, which we make available free of charge or at cost. Some of these materials have been translated for use in other countries, and we currently are sponsoring a physical therapist who is treating handicapped students and training staff at the Lae

Special Education Center in Papua New Guinea.

II. POSITION REGARDING S. 2053

As stated in testimony submitted at the February 27, 1984, hearing on this bill, we believe that S. 2053 would disserve the interests of America's retarded citizens for the following reasons:

1. S. 2053 would have the effect of closing all institutions for mentally retarded persons, including private institutions such as Bethesda.

2. S. 2053 assumes, without basis, that institutional care is universally inferior to small group care for all retarded citizens.

3. S. 2053 incorrectly assumes that community placement is always the least restrictive alternative, even for severely and profoundly retarded people.

4. S. 2053 would make it much more difficult for retarded citizens to exercise their religious freedom.

5. S. 2053 assumes, without basis, that the cost of implementing group home care for retarded people would be less than institutional care.

6. S. 2053 does not take into account the failures nor prevent repetition of the abuses which have resulted from previous deinstitutionalization programs.

7. S. 2053 ignores the effect of deinstitutionalization on families of retarded persons, on staff members who care for retarded people, and on the community at large.

8. S. 2053 is not a necessary prerequisite to the development of group home care.

III. REACTION TO AMENDMENTS PROPOSED BY VARIOUS ADVOCATE GROUPS

A. We agree with the following proposals:

1. We agree that persons over age 65 should have access to Medicaid-funded nursing home care without any time limitation. When people become elderly, many disabilities occur which place

impossible demands upon families and require extensive nursing support. Living in the family home under these circumstances may be more restrictive, regardless of whether the person is retarded or of normal intelligence.

2. We agree that protective services and case management should be available to any disabled individual, regardless of income or other assets. If assets are sufficient, however, the individual should be expected to pay for these services. Some proposals call for mandating such services - here we would urge caution, lest families be totally deprived of input and influence.

3. We agree that the appeal process should definitely be available not only to those moving from an institution to a home in the community but also to those in the community who believe they are inappropriately placed.

4. We agree that Medicaid should be available to children living at home for services they require - IF and only IF the family cannot afford such services.

B. We strongly disagree with the following proposals:

1. We do NOT believe that Federal Medicaid funds for persons in institutions should be phased down to 15% of the amount allowed for institutional care at the end of the 10-year time line of S. 2053. While 15% is an improvement over the total phaseout concept of S. 2053, it is NOT acceptable.

If the goal of this bill truly is normalization and equality of opportunity for all retarded persons, then it must be remembered that:

a. People of normal intelligence do have the freedom to choose where they will live and receive education and training, including institutional types of settings. For instance, these choices often include boarding schools for young people and colleges (in all parts of the country, often with the aid of federal loans and assistance) for adults. People with physical problems can go to outstanding hospitals and clinics throughout the country, with care being funded through a variety of government aid and insurances. Should retarded persons have less choices?

b. An institution CAN be the least restrictive setting for severely and profoundly retarded persons, especially those with physical disabilities and specialized medical needs. A good institution provides greater concentration of services and benefits for less expenditure of time and money than a community setting. With continued objections to increased taxation, we must not eliminate the most efficient way of providing services.

c. Some medically fragile people may always need or be best served in an institution. For these people, the two-year limit would be grossly unfair. There are some disabling conditions which require around-the-clock nursing care. When such people are in a small group home, what

happens when the scheduled nurse quits or becomes suddenly ill and no replacement is available? At Bethesda, individuals who are confined to bed are placed in carts and moved to other areas of the institution for treatment, training and recreation - a situation infinitely better than being confined to one room of a home in the community.

d. Others who may have greater freedom in an institution include those who are so low level that they have to be supervised constantly; some also need the routine and structure that only an institution can offer. Of even greater concern, though, are those who have behavioral disorders, psychotic tendencies or bad personal habits. They can be a danger to themselves and others - an impossible situation in a group home - and need the constant monitoring and safety which only an institution can provide.

e. Using the 10-year mark as the basis for continued funding at 15% or some other percentage does not take into consideration the shifting population of this country, especially the Sun Belt influx - nor the changes in the birth rate resulting from the cyclic baby booms, the next of which is predicted for the early 1990s.

2. We do NOT agree that private facilities should be required to meet the wage standards of public institutions. This would in effect take away the rights of private enterprise to determine salaries and job requirements. Private enterprise is basic to the American system and should not be limited by

additional laws of this type. Existing minimum wage laws are adequate.

At Bethesda, we hire an outside consulting firm which surveys salaries and benefits at hospitals and nursing homes in our region, and we seek to meet the average or higher. More than 50% of our employees have been with us for over five years. Last year we honored 10 employees who have served over 25 years here.

3. We do NOT agree that training of workers should be covered by the bill. Educational assistance in many forms presently is available to those who cannot afford education. Our field of employment should not expect something not offered to other industries.

4. We are further disturbed by the complexity of some of the proposed remedies for the problems which many have seen in S. 2053.

Some are so encompassing that they would make the bill a nightmare to administer. One example is the proposal to mandate adequate fee levels. Fees for services vary from state to state and region to region. Who determines what is adequate? And how? Competition, not government regulation, is the traditional American answer. To attempt to lure more health care professionals into service to retarded persons by raising the acceptable fees can only result in even higher costs in an already over-priced field.

Furthermore, the extension of a virtually unlimited, individualized array of services, as proposed by some advocates, could make the bill cost prohibitive.

IV. WHAT WE SUGGEST:

Needs of retarded people are as varied as there are people. How to meet those needs best is still the subject of great conjecture.

Many of the community experiments in serving severely and profoundly retarded children and adults have been performed under the most ideal situations. For example, a pioneering group home for severely retarded adults at Madison, WI, has functioned well - but staffing has been extremely heavy, and in addition, assistance has been provided by graduate students in special education courses from the University of Wisconsin. To compare this with a typical group home in a small community far from a university setting is illogical and should not be the basis for massive change.

Those who originally devised the concepts embodied in S. 2053 have tried many approaches to improving conditions for retarded people over the years. They are to be commended for their efforts. At the same time, it should be recognized that none of their successive approaches (more money for institutions; large community-based residential facilities; smaller group homes, etc.) have totally met those needs, and each has been abandoned in favor of a new idea, the latest of which is S. 2053. To assume that S. 2053 is the perfect answer, without sufficient data and research to support it, is a poor basis for doing away with excellent facilities (such as Bethesda) which are currently meeting needs of thousands of retarded people.

The result of this bill has been to alienate and polarize groups and organizations which have the same goal: improved

opportunities for retarded persons. It would seem, therefore, that it is time to agree on certain basics and then work together to find the best solutions. Those basics include the following:

A. Services must be determined by the needs of the individual - not dictated by a preconceived mind-set which says (without adequate proof) that BIG is always BAD, and SMALL is always GOOD. As reported in Sharon Landesman-Dwyer's 1981 study, "Living in the Community," (American Journal of Mental Deficiency, Vol. 86, No. 3), excellence is determined by staff attitude and by enthusiastic and creative leadership.

B. Costs of proposed programs must be assessed fully and appropriately, in fairness to Congress and the taxpayers. This must be achieved by comparing apples with apples. In figuring the costs of a group home, for instance, one cannot merely itemize basic care but must also include the additional services required. When an individual needs therapies, medical help and psychiatric care, it will cost as much or more to provide the same services in the community as it does in an institution, because, in addition to the fees of the professionals involved, one must also include transportation and the staff time to provide the transportation. Moreover, group homes which have been started in recent years to serve those with behavioral problems are already encountering high staff turnover and very high costs. For instance a group home of this type in Minnesota is now charging \$120 per day.

C. Solutions must not use the law to violate basic American principles, such as states' rights and the encouragement of

private enterprise. We must remember that government exists to do for people that which they cannot do for themselves. Since we cannot do everything for everybody, nor would we want to, we must then concentrate on the areas of greatest needs. In the field of mental retardation, this means providing services first for those who are severely and profoundly retarded - and not jeopardizing the good services which now exist for them. It also means not reducing their already limited freedom of choice, and it means learning from the bad experiences which mentally ill people have suffered because of deinstitutionalization programs.

Therefore, we propose the following:

A. Let's begin by insisting that existing laws be enforced for every institution in this country. Wisconsin has excellent inspection and enforcement; the federal government should make sure that other states do likewise. This alone would assure improved programming and eliminate abuse in all institutions. If we can't enforce those laws now, how can we hope to enforce them in thousands of new group homes and foster care homes in communities across this land?

We second Landesman-Dwyer's recommendation to the President's Committee on Mental Retardation in her 1981 study: "Develop a useful typology of residential facilities and services. Discard terms such as institution, community-based residence, and deinstitutionalization, none of which convey or imply information about program content or quality."

B. Authorize funding for group homes on the same basis as for institutions by expanding the Medicaid waiver and giving that

concept permanence. As we supplement rather than replace institutional care, the reduction and elimination of institutions will automatically occur if the various community living options do indeed prove workable and beneficial. People will clamor to participate in obviously good opportunities.

It takes time to develop good programs - more time than S. 2053 allows. In our impatience to cross new bridges, let's not destroy those bridges as we cross them, thereby cutting retarded persons off from that which is excellent in the present.

As M.J. Begab noted in 1975 ("The Mentally Retarded and Society: Trends and Issues," University Park Press, Baltimore), "it must always be kept in mind that the heterogeneity of the retarded population and the diversity of their needs militates against any single pattern or program."

C. Again we quote the Landesman-Dwyer study: "As much as possible, assess the quality of life from the viewpoint of individual clients - their personal preferences, needs and capabilities - rather than from our own perspective (e.g., 'Would I like to live here?')." All too often, in our zeal for doing good, we assume that what is best for people of normal intelligence and emotional stability is automatically best for those who are very retarded, those who have behavior problems and those who are elderly (and in some instances have died when forced to move to another home).

I would not want to live in a neighborhood surrounded by Einsteins - I would feel uncomfortable and out-of-place, never quite as good as anyone else. I most likely would have few friends and would be the object of the neighbor's pity or

ostracism. Yet this very situation is what ALL profoundly retarded people could be subjected to if S. 2053 becomes a reality - and they will have no place to return because the good institutions which now exist, the good institutions where they have found friendship and help and safety, the good institutions where they have made progress will no longer be an alternative for they will be closed.

Moreover, it takes time to change community attitudes, to train staff, to set up protections and programs - more time than S. 2053 allows. It took us three years to establish our second Illinois group home. We have been trying for an equal length of time to open a home in Maryland, but state requirements for education of staff make it almost impossible to find applicants. Iowa has laws requiring a group home staff person to be certified for distribution of medication, but fails to offer the certification course. An appropriate St. Louis site has proven difficult to find. GOOD group homes do not happen overnight.

Opportunists, lured by the potential for profit, are already entering the group home field in anticipation of passage of S. 2053. At the 1984 convention of the American Association on Mental Deficiency in Minneapolis, one organization was telling all who stopped at its display, "Do you know of any available group homes? We're buying."

Therefore, let us proceed under the Medicaid waiver to establish and test new programs. Let us move slowly and carefully, not through S. 2053, but through trial and testing until there is sufficient documentation to assure success rather than experimentation with the lives of precious people - our retarded friends and clients.